DOI:
10.3399/bjgp19X701861

Document Version
Peer reviewed version

BJGP British Journal of General Practice

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Journal:	*British Journal of General Practice*
Manuscript ID	BJGP-2018-0365.R1
Manuscript Type:	Article {qualitative} - Open Access
Date Submitted by the Author:	22-Nov-2018
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Keywords:	Diagnosis < Clinical (general), Cancer < Clinical (physical), Qualitative research < Research methods

BRAcED- PAPER 1 For BJGP

Missed opportunities for diagnosing brain tumours in primary care? Qualitative study findings

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ABSTRACT

Background

Brain tumours are uncommon, and have extremely poor outcomes. Both patients and GPs may find it difficult to recognise early symptoms as they are often non-specific and more likely due to other conditions.

Aim

To explore patients' experiences of symptom appraisal, help-seeking and routes to diagnosis to drive public awareness and service change.

Design and Setting

Qualitative study set in Eastern and NW England.

Method

In-depth interviews with 39 adult patients recently diagnosed with a primary brain tumour and their family members were analysed thematically, using the Model of Pathways to Treatment as a conceptual framework.

Results

Few (18%) presented as an emergency without having a prior GP consultation; most had one (38%), two (23%) or more (21%) GP consultations. Participants experienced multiple, subtle 'changes' rather than 'symptoms', often noticed by others rather than the patient, which frequently led to loss of interest or less ability to engage with daily living activities. Commonest changes were in cognition (speaking, writing, comprehension, memory, concentration, multi-tasking), sleep, and other 'head feelings' such as dizziness. Not all patients experienced a seizure, and few were experienced 'out of the blue'. Quality of communication in GP consultations played a key role in patient's subsequent symptom appraisal and the timing of their decision to re-consult.

Conclusion

Multiple subtle changes and GP visits often precede brain tumour diagnosis, giving possible diagnostic opportunities for GPs. Refined community symptom awareness and GP guidance could enable more direct pathways to diagnosis, and potentially improve both patient experiences and outcomes.

Keywords

Primary brain neoplasms; central nervous system neoplasms; symptoms; diagnosis; primary health care.

How this fits in

- National data suggest that people diagnosed with a brain tumour often see their GP several times before they are investigated or referred, frequently present as an emergency, and have poor outcomes.

- The findings from this study, interviewing people soon after their brain tumour diagnosis, suggests that whilst some present with headaches or major seizures, most are experiencing subtle, intermittent and multiple changes in their cognitive functioning, sleep and other 'head feelings' for many months, suggesting possible missed diagnostic opportunities.

- As these interviews were undertaken with patients and their family members soon after diagnosis, potential recall and social desirability biases affecting their reported experiences should be minimised.

- GP awareness of these subtle and intermittent changes or symptoms, and effective patient-GP communication with follow-up as safety netting, could alert them to more rapid investigation and referral and possibly reduce development of the significant and major symptoms associated with brain tumours.

INTRODUCTION

Primary malignant brain tumours are rarely diagnosed in primary care populations as the incidence is low: the age-adjusted incidence for the commonest type, glioma, is between 4.7 and 5.7 per 100,000 persons (1, 2). Outcomes remain poor despite improvements in treatment, so that although they represent less than 2% of all cancers they result in the most life-years lost of any cancer (3, 4). Most patients with primary brain tumours have seen their general practitioner (GP) prior to diagnosis, many several times (5), and more than 50% then present to, or are diagnosed by, accident and emergency services rather than by GPs or in specialist settings (6, 7). Indeed, only 1% are currently diagnosed via the 'suspected cancer' 2-week wait process, and via GP routine referrals (8), despite standardised NICE guidelines in 2005 (9), updated recently (10), and some intervening liberalisation of access to diagnostic imaging (11).

More timely diagnosis could improve patient outcomes, yet both patients and GPs may find it difficult to recognise early symptoms. In primary care, these patients can present with symptoms that are far commoner manifestations of benign conditions, making the diagnostic process very challenging (12). Over the last decade, a number of studies have used routinely collected English primary care data to quantify the frequency of the commoner presenting symptoms and their predictive values (13-15). However, a systematic review found that, apart from new-onset epilepsy and headache, these symptoms have low positive predictive values (PPVs) for brain tumours: even headache has a PPV of less than 1% (16). A recent analysis of brain tumour cases from the National Audit of Cancer Diagnosis in Primary Care showed the commonest presentations were with focal neurology (33%), 'fits, faints or falls' (21%) and headache (21%) (17).

Little is known about how patients appraise possible symptoms of brain tumours and make decisions about when, why or how they should seek help. However, qualitative research set among patients referred with possible symptoms of, or recently diagnosed with, other cancers has illuminated aspects of the symptom appraisal processes (18-21). This includes 'normalisation' of their symptoms if considered part of an expected ageing process, or if the symptom is vague, intermittent or non-threatening. Therefore, this study aimed to use similar qualitative research methods among patients recently diagnosed with a brain tumour to develop a richer understanding of their experiences of symptoms preceding diagnosis, appraisal of these symptoms, help-seeking, and routes to diagnosis to inform awareness and drive service change.

METHODS

Design and ethics

In-depth interviews were conducted face-to-face with adults very recently diagnosed (within 4 weeks) with a primary brain tumour in the East and North-West of England. The study was undertaken and reported in line with the Standards for Reporting Qualitative Research (SRQR) (22).

Setting and recruitment

Potential participants were identified and recruited by the neuro-oncology nurse specialists via the weekly neurosurgery clinics at two regional hospitals: Cambridge University Hospitals NHS Foundation Trust and The Walton Centre NHS Trust, Liverpool. These hospitals together serve a population of approximately 6 million, and the MDT meetings review more than 500 new cases of primary malignant brain tumours each year.

All adults aged 18 and over newly diagnosed with a primary brain tumour at the two participating hospitals were eligible for inclusion unless the neuro-oncology nurse specialists felt that they were not suitable on clinical grounds (severe physical or mental health conditions). Patients were given or mailed an invitation letter with a patient information sheet. Purposive sampling strategies were used to recruit a range of participants by age, gender and location to ensure that we had a broad range of views and experiences, and we continued until saturation of data. Sampling decisions and illness were the main reasons for not selecting patients for interview.

Data collection

Semi-structured interviews were carried out with patients and family members (usually spouse or child) in their homes between September 2016 and June 2017, following their diagnosis and before brain surgery. All present gave written informed consent to participate. An experienced researcher (CP) used an interview topic guide based on the aims of the research, available research literature (13, 16), and our collective expertise from interviewing patients recently diagnosed with other cancers (18-21). The guide was piloted, employed, and revised during the study as new issues arose. It focused on: when and how initial symptoms were noticed; the language used to describe symptoms and changes over time; the participant's decision-making and triggers to help-seeking; and experiences of the diagnostic process from the patient perspective. Interviews lasted between 45 and 90 minutes, were audio-recorded, professionally transcribed verbatim, checked and anonymised. Reflexive field notes were made following the interviews.

Analysis

Transcripts were imported to NVivo 11 software to support coding and data organisation. Inductive thematic analysis commenced soon after the beginning of data collection (23). We

started by defining each participant-reported patient interval (time from first noticing a change to first presentation, including the appraisal and help-seeking intervals) and diagnostic interval (time from first presentation to diagnosis) (24). The Model of Pathways to Treatment (25, 26) was then used as a conceptual model to underpin the remaining analysis. A coding frame based on this model was developed with the first few transcripts, applied to the subsequent transcripts, and refined iteratively, applying a constant comparative method (27). When the first consultation did not result in referral, we also included further iterative processes in the analyses. Members of the 'core' research team, from a range of clinical and non-clinical backgrounds, read all the transcripts, and met regularly to resolve coding issues, and further refine the coding framework. Codes were compared both within and across interviews, and then grouped into key themes and sub-themes. These were agreed through a series of meetings involving the 'core' researchers, the two consumer members of the research team, and consensus meetings with the wider study team including neuro-oncology experts.

The analysis focused on two main areas: 'symptoms' experienced prior to a brain tumour diagnosis and how these were reported and responded to in primary care, is presented here; and the psychological approaches underpinning the appraisal and help-seeking processes, often over several consultations, is reported elsewhere (28).

Workshop – triangulation of early findings

We shared early findings at a workshop supported by our funder The Brain Tumour Charity, including GPs from London (n=10), and patients (n=7) and carers / family members (n=9) affected by brain tumours drawn from across England. Four mixed and facilitated focus groups were undertaken for credibility checking. These lasted up to one hour each, were audio-recorded, transcribed verbatim, checked, anonymised, and analysed to search for concordant, discordant, or new data. With reference to this analysis, the findings were entirely supportive, and no new data were found.

RESULTS

39 people were interviewed: their mean age was 53 years and 46% were female. The commonest diagnoses were glioblastomas, located in the frontal region (**see Table 1**).

Although headache and seizure (without preceding symptoms) are generally considered the commonest presenting symptoms in primary and emergency care, we found that headaches and seizures were only reported by half the participants (21, 55%). More reported changes in cognition (26, 68%) and sleep (22, 58%). Furthermore, almost all participants (38, 97%) had noticed multiple changes or symptoms prior to either routine or emergency presentations.

Four main themes were identified in participants' narratives: (1) people experience 'changes' rather than 'symptoms', often first noticed by others; (2) multiple, subtle changes precede brain tumour diagnosis; (3) not all seizures are the same and few come 'out of the blue' (that is, without any prodrome), and (4) patient-GP communication. These themes are presented in detail here, with quotations contextualised with the participant's ID number, gender and age group.

1. People experience changes rather than symptoms, often first noticed by others

Participants frequently described 'changes' or 'something not quite right' rather than 'symptoms'. Some changes related to their body, and others to the way they approached daily living activities, work, hobbies or relationships (see **Diagram 1**).

Some changes were very subtle and difficult to notice – sometimes the participant was unaware of changes until someone else pointed it out.

> *'I felt okay, I didn't feel as though there was anything wrong with me, but looking back now I can see what [wife] was worried about.' [30, M, 71-80]*

Sometimes friends or family had noticed a change, but did not say anything until after the participant had been diagnosed:

> *'People… wouldn't say anything at the time but now they say, "We noticed you haven't been quite yourself for 6 months," but they are little things that people wouldn't say, "Go to the doctors and get sorted…"'[10, F, 61-70]*

2. Multiple, subtle changes precede brain cancer diagnosis

Diagram 1 and **Table 2** demonstrate the diverse range of changes experienced that made the participant think '*that is not me'* or a person close to them report '*you weren't quite yourself*'. Experiencing these changes or symptoms often led to less engagement, less interest or a change in ability to carry out work, hobbies, caring responsibilities and daily living activities. 'Seizure' does not have a separate locus in the diagram as any of these changes could precede or be a part of a seizure.

2.1 Changes in cognitive function

2.1.1 'Brain not working properly'

People described not being able to do things as they used to, or being less accurate or not '*on the ball*'. Some people noticed very subtle changes, whereas others described having to put extensive thought into everyday tasks. Cognitive changes often made people feel frustrated, irritated, confused or anxious. Participants and their family described four main types of changes in cognitive function as outlined below:

2.1.2 Changes in speaking and writing

Many participants and their family noticed that speech changed, often intermittently. Some experienced difficulty finding or saying words, while others noticed odd sentences with random words. Many also mentioned problems with spelling: text messages or emails becoming full of errors, or lacking sense. Participants found texting became more difficult and took longer, leading some to replace text with emoticons or stop sending texts altogether.

2.1.3 Changes in comprehension

Most participants noticed a change in their understanding or processing of information. For some, it was understanding what was being said, or how long it would take to complete tasks. The greatest impact was on reading: some reported having to frequently re-read text or stopped reading altogether.

2.1.4 Changes in memory

Memory was affected in a range of situations, including forgetting: where they had left objects; what they were doing or thinking about in the moment; completing tasks as intended; or names or places.

2.1.5 Changes in concentration and ability to multi-task

Some noticed that they were struggling to concentrate or focus. Others found they could only concentrate on one thing at a time, and therefore developed difficulty with multi-tasking.

2.2 Changes in sleep

For some, sleep became disrupted and they often struggled to go to sleep, frequently waking up, not sleeping well or waking earlier than usual. Others described sleeping more than normal, by either going to bed earlier or waking up later. Some started having daytime naps because they felt an urgent need to close their eyes and rest, or because their night-time sleep was disrupted: these people described feelings of extreme tiredness.

2.3 'Head feels like…'

2.3.1 *'I wouldn't say it's a headache…'*

Many participants felt strange sensations in their heads. Rather than calling them a headache or pain, they were described as feeling: '*muzzy', 'fuzzy', 'thick', 'fluttering'*, or '*coming in a wave'*. Some spoke about temporary feelings of dizziness or light-headedness, described as 'like being drunk', and giddy. One example had occurred every 2-3 weeks over

the preceding year: *"not dizziness, not losing balance, not anything to do with your eyes, just literally the sensation of my head doing a little spin." [12, F, 51-60]*

2.3.2 A new or different headache

Many participants spoke about having changing headaches such as new onset headaches, a headache with increased intensity or duration, or one that felt different to 'a normal headache'. Some described these headaches as constant or daily. Some spoke about experiencing painful headaches that were severe and unbearable: their pain was described as feeling like pressure, pulsations, piercing, drilling, and fireworks. Some noted they had started taking painkillers regularly.

2.4 Changes in balance, sensations and senses

2.4.1 Body parts weak or not working

Participants spoke of weakness or numbness in parts of their body, or that body parts '*just didn't work*'. Some experienced sensations such as pins and needles, tingling, twitching or shaking in that part of the body, and, for some, this was later recognised as due to a seizure. When these sensations were noticed in upper limbs, some found that they dropped objects or felt clumsy or unable to hold everyday objects. Facial changes could result in dribbling, slurred speech, or difficulty talking. Weaker lower limbs were mainly manifested by slower walking or changes in a person's ability to drive. Participants noticed changes in balance or becoming unstable. They spoke about leaning to one side, wobbling, staggering, tripping, stumbling, hovering and sometimes falling.

2.4.2 Changes in vision

Some participants noticed that their eyesight or ability to focus deteriorated, experiencing blurred or double vision (sometimes intermittently) or were squinting or straining to see. For others, their field of vision was reduced. A few participants spoke about experiencing a tic in their eye.

2.4.3 Changes in hearing

A few participants experienced sensitivity to noise. Others felt their hearing was compromised, predominantly on one side, as if the sound was muffled or their ear was wrapped in cotton wool. Such changes meant that these people were straining to hear, asking people to repeat what they were saying or lip reading.

2.4.4 *Changes in taste or smell*

A few participants spoke about a metallic smell or taste that was particularly strong at times; this was sometimes subsequently attributed to a seizure.

2.5 Change in person: 'out of character'

Participants and family members compared recent moods, attitudes or behaviours to how the patient had previously been. Participants mostly knew they were 'out of character'; some had been apologetic for their change, or articulated that they did not know why they were acting in a different manner. A number of personality or emotional changes were mentioned, including becoming more irritable, angry, anxious, overwhelmed or sensitive than normal. Other changes included lack of social inhibitions or change in social interactions. Some were aware of a sense of lethargy that they had not had in the past, describing lack of motivation or disinterest, and commonly using the phrase "*just can't be bothered*" about work and hobbies.

3 Not all seizures are the same or come out of the blue

Not all seizures were the same: they differed between participants and over time. Participants spoke of experiences that were '*out of the norm'* and unwanted, yet still 'understandable' such as having déjà vu, panic attacks, sleepwalking, or intrusive daydreams. Participants explained their symptoms as a 'simple' response to being tired, having over-exercised or not eating. Symptoms that were more intrusive led some participants and their family members to think they were experiencing a stroke. People experiencing a seizure often did not seek help initially, and the timing of the decision to seek help was often driven by a seizure involving a collapse. However, not all patients collapsed, and some chose to visit their GP rather than A&E for seizure symptoms.

> *'I would feel, "Ooh, that's a bit strange," I'm just overtired or there's been a little reaction and it just didn't seem to make sense […] They were so spasmodic then that it was easy to put it down to just being over-tired and a bit overwrought at work, really.' [02, M, 51-60]*

> *'I thought it was like panic attacks. […] It started off with little twitches and obviously, you don't really pay attention but now they're getting like my arm will flare up, my leg will twitch up that way.' [06, F, 31-40]*

> *'I just thought they were intrusive daydreams or funny repetitive thoughts … it was that déjà vu sort of thing […] I just thought this must be some weird baby brain.' [07, F, 31-40]*

4 Quality of patient-GP Communication

Patients spoke about the considerable consequences of subtle differences in discourse during GP consultations (see **Table 3**) and these were reflected in the patient, carers and

GP's suggestions for how to improve GP consultations to reduce missed diagnostic opportunities (see **Table 4**).

4.1 Selective or limited disclosure

Patients discussed some of the changes/symptoms with their GP, but often failed to mention all the changes they had noticed because they forgot, or were reluctant to give more details, or found the consultation too short. Some noted that they were uncertain about which changes were important to discuss. Conversely, some were prompted by their GP to reveal more details, which, in turn, could led to a decision to refer the patient for further investigations.

4.2 Alignment of views

Patients generally attended their GP with ideas about the cause of their symptoms. Sometimes patients felt disappointed when told nothing was 'wrong' yet they continued to experience symptoms, and spoke of believing they had been 'fobbed off' or 'brushed off'. In some cases, the GP agreed with patient's views and subsequent investigations aligned with patient suggestions. However, the GPs disagreed with the patient's suggestions in many more instances. A brain tumour was not initially considered by the GP or the patient; instead, other diagnoses such as infection (viral, ENT), hormonal changes (thyroid, menopause), eye problems or mental health issues were considered more likely and investigated first. Once these diagnoses had been ruled out and the patient decided to re-visit their GP, a CT scan was more likely to be arranged during subsequent consultations.

4.3 GP response impacts decision to re-consult

When GPs appraised symptoms and gave plausible explanations, patients spoke of feeling reassured; sometimes this gave patients less incentive to re-attend when symptoms continued. If patients felt their symptoms were dismissed or not given attention by the GP, this prompted them to downplay their symptoms and again, their motivation to re-consult was low.

Some patients spoke about the GP specifically asking the patient to return, with some booking the appointment for the patient. Others felt that there were missed opportunities to obtain a quicker diagnosis because they were not actively encouraged to re-attend if test results were negative, or symptoms persisted or developed. A few also spoke of long times between appointments, slow or forgotten referrals, or scan results not reviewed.

DISCUSSION

Summary

As far as the authors are aware, this is the first study to explore patient experiences along the pathway to primary brain tumour diagnosis. It provides a rich understanding of how people and their family and friends try to make sense of subtle, intermittent and often multiple changes in their functioning and well-being before they are even identified as 'symptoms'. More than half our participants and their family members noticed a combination of physical and cognitive changes for over six months before seeking help, and many went on to have multiple encounters with GPs and other healthcare professionals before either referral and appropriate diagnostic imaging, or accelerating symptoms leading to emergency presentation.

Strengths and limitations of this study

This sample was diverse with respect to age, type and stage of brain tumour at diagnosis, and drawn from two regions of England characterised by diverse socioeconomic circumstances. Importantly, the patients were interviewed within a few weeks of their diagnosis and prior to neurosurgery, facilitating recall of the subtle and intermittent 'changes' or symptoms they had experienced over the preceding months. They were also encouraged to have a family member present during the interview. Both approaches should minimise recall bias. The authors believe that they achieved saturation of data as no new themes were identified in the later interviews. Furthermore, the workshop for GPs, and other patients and their family members, gave us an opportunity to triangulate our analysis and check the credibility of our early findings, plus confirming saturation.

The main limitation was that the participants were often unwell when we interviewed them, and sometimes apprehensive about their imminent major surgery. While they were altruistic to wish to contribute to our research, their condition sometimes led to difficulties in communication, or to reliance on family members to 'talk for them'. There may have been differences between the 'public' accounts given in the interviews, often in front of loved ones, and participants' actual experiences and views. However, this work still provides important insights into the subtle and intermittent changes which can precede a brain tumour diagnosis and potential missed diagnostic opportunities.

Comparison with existing literature

These findings are consistent with previous work, which shows that non-specific symptoms often precede brain tumour diagnosis, making both patient presentation and GP assessment

for further investigation or referral problematic. This can result in multiple GP consultations, emergency presentations, and longer patient pathways (17, 29).

A recently reported epidemiological study, analysing brain tumour cases from the National Audit of Cancer Diagnosis in Primary Care, grouped neurological symptoms into six domains: headache, behavioural/cognitive change, focal neurology, 'fits, faints and falls', non-specific neurological, and other/ non-specific (17). However, our findings have identified a far wider range of subtle and often intermittent symptoms, more frequently referred to as 'changes' by the patients, and suggests that the GP case-note audit approach may not have identified people presenting with changes in sleep, and feelings in their head, not identified as a headache. There may also be a recording bias in primary care records studies, as GPs tend to record a single or the most significant symptoms, and there is neither the time nor the codes for recording more subtle or complex presentations, or the terms used by the patients to describe the changes.

Implications for research and/or practice

Clinicians continue to consider seizures and headache as the main presenting symptoms of brain tumours (30). However, our findings have shown that patients notice other changes and symptoms for many months before presentation. Studies using qualitative approaches have contributed to a deeper clinical understanding of the development of other serious conditions such as pancreatic cancer (31) and meningococcal disease in children (32). Clearly, our qualitative findings, drawn from a small sample of patients soon after their brain tumour diagnosis, now need to be validated in a larger cohort. If generalisable, our findings could lead to tailored awareness campaigns for adult patients and educational approaches for GPs in a similar way that 'HeadSmart: Be Brain Tumour Aware' was launched in the UK in 2011, following the recognition that the median total diagnostic interval was three times longer for children in the UK than in the US (33). This guidance on symptom awareness, assessment, investigation and referral has been shown to enhance awareness among health professionals and the public, and appears to have led to a significant reduction in the UK's total diagnostic interval (33, 34).

Non-specific early symptoms of brain tumours can contribute to diagnostic delays, and possible disease progression. GPs seeing patients with these non-specific symptoms, such as mild cognitive changes or sleep changes, should be able to identify patients who warrant further investigation without an increase in unnecessary brain imaging which may expose incidental abnormalities. GPs could benefit from a triage tool, particularly one that is low-cost and accessible in primary care, such as the GPCOG to elicit cognitive and functional changes indicative of dementia (35). A promising new approach is a serum-based spectroscopic tool that can detect disease-specific signatures (36); this has been shown to be a potentially cost-effective addition to the brain tumour diagnostic pathway (37), and is

currently under development as a triage tool for primary care. Furthermore, recent advances in molecular biology have improved understanding of glioma pathogenesis, with genomics now combined with histology in the revised 2016 WHO classification of CNS tumours; this could contribute to biomarker-based early detection of brain tumours in the future (38).

In summary, while subtle and intermittent changes or symptoms are almost universally experienced with age, and may occur with headache, GP awareness of the changes preceding brain tumour diagnosis, and effective patient-GP communication with follow-up as safety netting, could alert them to more rapid investigation and referral and possibly reduce development of the significant and major symptoms associated with brain tumours.

ACKNOWLEDGEMENTS

Funding

This study was supported by a grant from The Brain Tumour Charity (GN-000316 - BRACED: The BRAin Cancer Early Detection study). Fiona Walter and Willie Hamilton are Directors of the multi-institutional CanTest Collaborative which is funded by Cancer Research UK (C8640/A23385). Colin Watts is funded by the Brain Tumour Charity and CRUK.

Ethical approval

Cambridge South NRES Committee, East of England: 16/EE/0179.

Competing interests

None

Acknowledgements

We thank all the patients and their family members who have so willingly shared their experiences at a very difficult time.

We also thank those who contributed to recruitment, at the Cambridge University Hospitals NHS Foundation Trust: Rocio Fernandez Mendez, Rebecca Rastall and Will Sage, and at the Walton Centre NHS Foundation Trust, Liverpool: Carole Hewitt and Andrea Clyne. We are grateful to collaborators who contributed to this work: our clinical and academic collaborators Dr Sarah Curtis and Anna Wood, and our PPI representative Joyce Bell.

Table 1: Characteristics of participants, reported encounters with primary and emergency care for symptoms of subsequently diagnosed brain tumours, and clinical characteristics of their brain tumours

	Participants (n=39)
Age at interview Mean age (range) 53 (22-74)	
21-40	10 (26%)
41-60	15 (38%)
61 and over	14 (36%)
Gender	
Male	21 (54%)
Female	18 (46%)
Region of England	
Eastern	30 (77%)
North Western	9 (23%)
Patient Interval (first symptom to first presentation)*	
< 7 days	5 (13%)
1 - 4 weeks	3 (7%)
1 - 6 months	10 (26%)
7 - 12 months	11 (28%)
> 12 months	10 (26%)
Diagnostic Interval (first presentation to diagnosis)*	
< 7 days	1 (3%)
1 - 4 weeks	16 (41%)
1 - 6 months	15 (38%)
7 - 12 months	5 (13%)
> 12 months	2 (5%)
Reported consultations with GPs in primary care	
0	7 (18%)
1	15 (38%)
2	9 (23%)
3+	8 (21%)
Reported consultations with emergency care	
Emergency only (no contact with GP)	7 (18%)
Emergency care with contact with GP	
- GP contact prior to emergency care	14 (36%)
- GP contact after emergency care	1 (3%)
- GP contact before and after emergency care	5 (13%)
No emergency care	12 (31%)
Tumour type	
Diffuse astrocytoma	5 (13%)
Anaplastic astrocytoma	4 (10%)
Oligodendroglioma	2 (5%)
Anaplastic oligodendroglioma	2 (5%)
Glioblastoma	22 (57%)
Other astrocytic tumours	2 (5%)
Unknown	2 (5%)

Tumour location	
Frontal (including fronto-parietal x 2)	20 (51%)
Temporal	10 (26%)
Parietal (including pariento-occipital x 2)	4 (10%)
Occipital	2 (5%)
Other (thalamus x1, tempero-insula x1, n/a x1)	3 (8%)
WHO Grade	
Low grade: II	8 (21%)
High grade: III/IV	7, 22 (18%, 56%)
Ungraded	2 (5%)

* Participant account, not confirmed from clinical records

** 5 of whom also visited a GP after emergency care

Figure 1: Detecting brain cancer earlier: 'You weren't quite yourself'

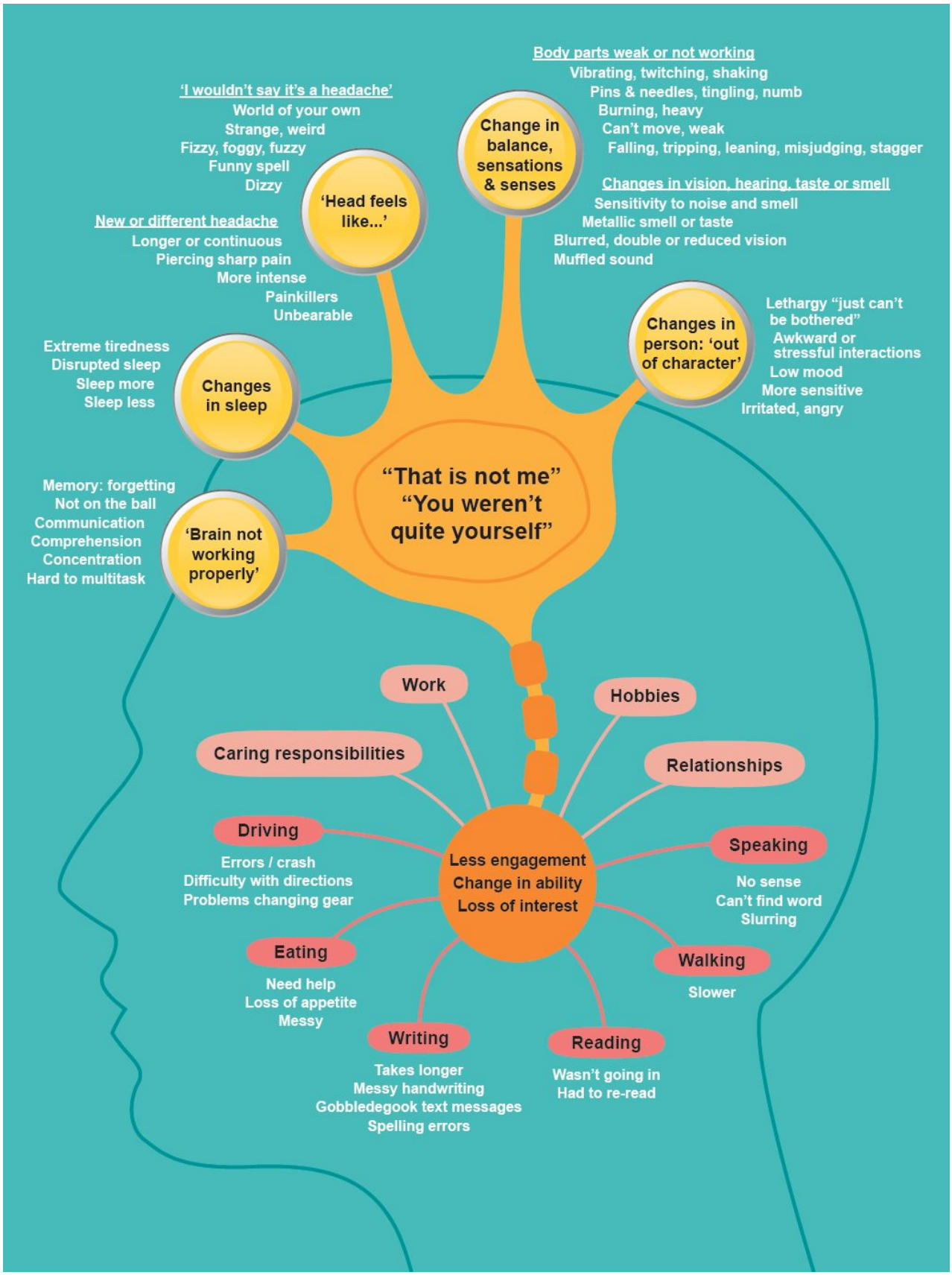

Table 2: Multiple, subtle changes precede brain cancer diagnosis

2.1 Changes in cognitive function
2.1.1 'Brain not working properly'
'Whether it's standing up or crossing the road or getting out into the garden or anything like that, I have to think about it or I have to plan my route.' [17, M, 61-70] *'If I'm trying to do something, sometimes you have to stand there for about 5 to 10 minutes and figure out how I was going to do it.' [33, M, 51-60]* *'I could feel myself getting a bit slower in work. I was struggling to do and think of all the things that I'd normally do […] I just knew I wasn't as quick and I couldn't think ahead as much and it just wasn't the same.' [37, F, 31-40]*
2.1.2 *Changes in speaking and writing*
'I'm trying to say something… I can think it, but it doesn't really come out. I can't find the right words, really.' [39, F, 21-30] *FAMILY: 'I said, 'What are you talking about?' He said, "The control handle, you know, the vegetable man."I thought, no, this isn't right, this isn't right at all.' PATIENT: 'I started trying to make conversation with you and it was just random words and rubbish.' [28, M, 51-60]* *'I'm normally a pretty good speller, but I couldn't remember how to spell words and writing up notes at work was a bit of a concern cos I was forgetting how to spell.' [03, F, 31-40]* *'Total gobbledegook, because I pushed the wrong key, predictive text. So then I took the predictive text off, but then it was even worse. It could take me ten minutes to write an email.' [32, M, 71-80]* *FAMILY: 'The messages we got, they were, like, all in a funny order.' PATIENT: 'Terrible. That's why I stopped texting because I was getting bad at that.' FAMILY: 'Then there was another one with flames […] and I thought, "What an earth's he on about?" and then I found out afterwards. He was trying me to get him some cigarettes.' [33, M, 51-60]*
2.1.3 Changes in comprehension
'I've been trying to read this book and it's breaking my heart because I can't get it, and I've read every book by this author.' [33, M, 51-60] *'Although I was having trouble reading, I was also having trouble understanding what the words were saying […] I couldn't be bothered to read because even if I could read it, I didn't really understand what it was telling me anyway […] The plot was disappearing every other page.' [32, M, 71-80]* *'I've got this catch-up, it takes me a while to realise what they've said and quite often I'll ask them to repeat it or sometimes it just takes longer to have got through.' [24, F, 41-50]*
2.1.4 Changes in memory
'Probably [for] the last six months, they all used to laugh at me and just say "Who's got more dementia, you or your mum."' [05, F, 41-50] *'Remembering things and how to do things has progressively got worse. I've been finding that I'm a bit numb in my head.' [31, M, 41-50]* *FAMILY: 'He kept forgetting things. He kept forgetting people's names. And places. He couldn't remember.' PATIENT: 'People I've known for 40 years, I couldn't remember names. Really couldn't and that's what really upset me.' [33, M, 51-60]*

2.1.5 Changes in concentration and ability to multi-task
'Whereas before that he could get to work with his eyes closed basically, he was actually questioning himself, "What have I got to do next? What am I here for?" that sort of thing. He… kept saying, "I can't concentrate."' [19, M, 61-70] *'I was trying to plait her hair and test her on the spellings and I had a funny turn and it was just too much, I just couldn't cope with looking, listening and doing.' [37, F, 31-40]* *'If I wanted to do something, I could concentrate on two, three things, run them all at the same time. Now I can't, one thing at a time.' [33, M, 51-60]*
2.2 Changes in sleep
'I've literally pulled my car over, closed my eyes and gone to sleep, which is unheard of [as] I've never found sleep that easy.' [03, F, 31-40] *FAMILY: 'You always used to go to bed about half-past 10 didn't you? But then that got to 8 o'clock didn't it?… And then just before he was really poorly, come half-past 7 he would say, "I'm going up."' [19, M, 61-70]* *'I have been sleeping more. In the afternoon I was getting so tired… I never used to do that before, and I started napping in the afternoon.' [38, F, 51-60]* *'I mean, I was just, well, tired, exhausted… I was feeling absolutely totally shattered.' [15, M, 51-60]* *'I'd quite often fall asleep with the laptop on my lap, trying to do paperwork […] I would find myself nodding off quite a bit.' [29, F, 41-50]* *'I really struggled in work […] especially if there were quiet times. I feel like I could've easily fallen asleep and I just put it down to not sleeping at night. Looking back, I definitely had a change in my pattern of sleep.' [39, F, 21-30]*
2.3 Head feels like…..
2.3.1 'I wouldn't say it's a headache…'
'I can only describe it like a sherbet bomb in my head […] like that fizz bomb you have in the bath […] but not painful, not uncomfortable, not anything… I would lay down and there would be a little bit of fizzing. No big deal, it wouldn't last forever, but you know, just aware of what a strange sensation that is.' [27, F, 71-80] *'I wouldn't say it's a headache, but you get like a little pain in the front of your head and it goes just like that. It's almost like a wave.' [34, M, 41-50]* *'It felt like there was always too much in it and a bit foggy […] it felt like it was full of fog.' [13, F, 31-40]*
2.3.2 *A new or different headache*
'Normally, if I have a headache, give it a couple of hours and it'll go away, but it wouldn't. I couldn't figure out how to get rid of it each day.' [33, M, 51-60] *FAMILY: 'Before any of this started, [when] I've been getting up for work he'll say, "God, I've got a terrific headache," which… you never get headaches do you?' [30, M, 71-80]* *'I've had headaches probably for the last 18 months on and off, quite severe really, every single day, pretty much without fail.' [03, F, 31-40]* *'Very piercing… they would shoot across the back of [my] head or across [my] forehead… I could stand there, I hadn't got a headache, all of a sudden, it was like somebody had put a needle in [my] head.' [13, F, 31-40]* *'That was a pretty extreme headache because I don't get headaches, but if I do, I really don't normally need a paracetamol just to get through it.' [32, M, 71-80]* *'I do voluntary for the charity shop; I ended up having to keep phoning them up and saying "I can't come in today" because I keep having really bad migraines.' [31, M, 41-50]*
2.4 Changes in balance, sensations and senses

2.4.1 Body parts weak or not working
'When I first noticed it I was at work normally, and I wasn't even doing anything. And then all of a sudden my three fingers on my right hand just locked.' [34, M, 41-50] *'You know if you have a really dead arm, and then the feeling comes back, and it sort of prickles and it stings rather like stinging nettles, and feels very heavy.' [12,* F, 51-60] *'I was getting a tingling round the top of my head, progressing down the left side of my cheek, and… it went down my arm. I went "That's a bit strange, that."' [35, M, 41-50]* *'I always sat here with a roll-up […] I did notice I was dropping it, it was annoying me that I was dropping it.' [27, F, 71-80]* *'Eating breakfast […] my hand wasn't working quite well enough with the spoon.' [04, M, 61-70]* *'When I was eating I was a bit messy on this side and he'd go, "Wipe your mouth." And I would go, "What are you on about?"' [10, F, 61-70]* *'I noticed that I was slurring my words and wasn't able to say some syllables. When I was leaving a voicemail message on an answer machine, I had to repeat myself to get the thing out.' [21, M, 51-60]* *FAMILY: 'I noticed it because you were walking around as if you was about 90 years old, you sort of like hunched over and your legs were really slow and you were just wobbly the whole time.' PATIENT: 'Yes. I could hear my foot drag along the ground.' [16, M, 61-70]* *'I didn't fall over, I was just a little bit unsteady. I can walk normally but not on a line, you know like when a policeman wants you to walk on a line for being tiddly? I couldn't do that.' [11, M, 71-80]* *'As I was walking up the hill it was almost like I was blind drunk, I was just staggering to the left all the time, fell into the wall a few times.' [09, M, 61-70]* *'Just the stumbling back when you get up off the loo that sort of thing and putting my left hand out to the side just to stabilise myself, yeah… [also] I could go a bit black, a bit dizzy […] when I look up it would send me off balance […] my head would go like you've been on a rollercoaster […] and you just want to stabilise yourself a bit.' [03, F, 31-40]*
2.4.2 Changes in vision
'If I concentrated on something then I could quite easily get blurred vision.' [08, M, 61-70] *'You know when you're dreaming and it's hazy or like you can't see properly, it's like that… like a blur… It's more cloudy, like a mist comes over my eyes...' [06, F, 31-40]* *'I kept getting a really twitchy eye, it was so irritating, in the right one, it was twitching like crazy and I got that a few times in the last few months.' [24, F, 41-50].* *PATIENT: 'I was drifting to the left all the time.' FAMILY: 'He were driving right close to other cars that were parked or anything that's this side… so I had to keep telling him to go back to the middle of the road.' [17, M, 61-70]* *'So if something comes at me from that direction, I'll hit them. Perhaps I tripped up a bit, blamed it on the fact I couldn't see… I'm not talking lots of times, but perhaps I've fallen over three or four times, you could blame that on my eyes as well.' [32, M, 71-80]*
2.4.3 Changes in hearing
'If the kids make a noise upstairs I haven't been able to handle it very well, so I've noticed a big increase in sensitivity to the light and the noise […] everything was just heightened, the dog barking and things like that it would make me very irritable.' [03, F, 31-40] *'Less sensitive if anything, like cotton wool in my ears.' [38, F, 51-60]* *'I found myself kind of turning to hear with my good ear and things like that […] when my colleague speaks to me… she's further into the room… I have to really try and lip read what she's saying. I can still hear but just not very well.' [23, F, 21-30]*

2.4.4 Changes in taste or smell
'I had had this funny smell… I don't know if it's a bit metal-y or a bit fuel-y, maybe workshop-y I suppose.' [07, F, 31-40]
2.5 Changes in person: 'out of character'
'I'd just go nasty and just give him grief for nothing.' [05, F, 41-50] *FAMILY: 'He's such an easy going man normally, and at home I noticed he's been a bit snappy with me as well and I just noticed it, odd snaps at me.' [17, M, 61-70]* *'Not being as tolerant and as thoughtful and as considerate as I would probably expect myself to have been. […] I thought I was being totally irrational and not reasonable, and unfair and unkind.' [02, M, 51-60]* *FAMILY: 'It was subtle changes in his personality where he was a little bit inappropriate. And I've never had to worry about that, you know, I mean he can be quite outrageous when he's being funny, but it's within the realms of absolutely fine. And then I started to worry about what he was going to say, who he was going to wind up, yeah, just how far he might go.' [20, M, 71-80]* *'I thought things were getting on top of me, I have a lot to do, and I thought, "My God, I'll never catch up." I wasn't panicking exactly. I just wasn't 100%.' [11, M, 71-80]* *'I was very anxious, I have to admit, very anxious. I knew there was something wrong, but it was the simple fact I couldn't figure it out.' [33, M, 51-60]*

Table 3: Patient-GP communication

4.1 Selective or limited disclosure to the GP
'I keep forgetting and every time I go, "I forgot to tell them about my twitches."' [06, F, 31-40] *'What did I tell him... I was feeling really lousy and what have you… at that point I didn't actually say I've just crashed the car through... I didn't.'* [27, F, 71-80] *'I just said, "I'm a bit fatigued, people are a bit concerned about me," but I didn't go into any detail…The trouble is when you go to the GP it's always like a rush.' [09, M, 61-70]* *FAMILY: 'You don't know what information to offer the doctor because you don't know what's relevant and what isn't. So for [PATIENT] to go and not know, you needed someone to ask the leading questions …and then put a picture together for you. Rather than just sit there.' [26, F, 41-50]* *'I said, "I've got a migraine" and that was it, that was pretty much all the information I was willing to give and then he said, "Okay, well what else has been going on?" And then he made me go through the past four weeks like what you did and then got me to describe the migraine in detail and prompted as well.' [36, F, 21-30]*
4.2 Alignment of patient and GP views
FAMILY: 'You went to the GP about a month ago and said then that you'd been having these feelings of not feeling right and not being able to articulate your speech and thoughts. …He did a preliminary dementia test, because [PATIENT] was worried that he was getting Alzheimer's.' [02, M, 51-60] *'I went to him, "I need you to check to see if I'm going through the menopause" and he went, "Oh"… and then so he went, "I don't think it's your hormones."' [06, F, 31-40]* *'I think I might have carpel tunnel syndrome because I'm getting these twitches in my hand. And I explained them to him and all he said was, "That's not carpel tunnel syndrome."' [34, M, 41-50]* *'I think I felt a bit fobbed off with it really… cos [GP] would just look at you and if something wasn't physical or if something wasn't fitting in with what he thinks he just didn't have anything to do with you.' FAMILY: 'You felt like as if you've been brushed off.' [31, M, 41-50]* *FAMILY: 'We took you to the doctors that's right and then we came home and he told you to go back in a fortnight and he thought [it] was depression and I thought I don't think it's depression but of course I hadn't told him about the symptoms with his leg and hand. I thought he had had a slight stroke.' [30, M, 71-80]* *'He obviously was really quite concerned what I had told him but… he said, "I think it's stress." I don't normally disagree with a doctor but I said, "I'm sorry, I don't think it is stress." …But he said, "We don't always see stress in ourselves." He just said, "Would you perhaps consider that it might be stress?" I said, "Okay."' [03, F, 31-40]*
4.3 GP response impacts decision to re-consult
'When I said, "Well, still got the headaches", it didn't [seem to] matter… So I never went back to my doctors I just took it that they were saying that the headaches were okay.' [05, F, 41-50] *'I was getting to the stage where I thought, well maybe it is just something that will disappear and, you know, they don't seem too worried about it so I left it for a long time.' [23, F, 21-30]* *'I said to him about that and he just, without being horrible, he wasn't really interested… So then I didn't think it was that big an issue because if it was he'd have looked into it more… So if he dismisses it like that and he's a doctor then, you know.' [34, M, 41-50]*

'When I went with the headaches I think she sort of laughed me out of the surgery and said, "Well everyone gets headaches." And you think, I won't come back again, thanks for that.' [03, F, 31-40]
4.3 Follow-up as safety-netting
'Well, I just feel [my doctor] should have said, look, if your eye test comes back clear, come back and we'll have another look at you, and we'll investigate it. …But you listen to what your doctor says and because they never said come back... I just feel they just sort of brush you off.' [05, F, 41-50] *'You think that if you'd got something that is progressively carrying on over a long period of time that you would get to a stage where you think that you would investigate this a bit more.' [31, M, 41-50]* *'And said he'd never seen anything like it before, if it carries on go back. So about a month later I went back again.' [34, M, 41-50]* *'She said, "Don't worry about it too much and come back and see me in a little bit," which is fair enough… She made an appointment for me to come back I think.' [07, F, 31-40]* *FAMILY: 'He said he was a good doctor, so and he had his bloods done, sent him around the corner to do his bloods and his urine and then we had to go back.' PATIENT: 'And he got in touch with me a little bit later and put me in for a MRI scan.' [17, M, 61-70]* *'They didn't send me to A&E, they sent me to a specific clinic where she'd obviously rung in front, because they were waiting, and a couple of days later, and she only works two days a week at the surgery, she actually phoned up [SPOUSE] to check that everything went well. So I suspect when I walked in the door, she knew there was a problem.' [32, M, 71-80]* *'I went back again on 18th February, so that was two and a half weeks later, and I saw a different doctor and said again, you know, it's not cleared, it's not doing anything, it's not even slightly better… I was getting to the stage where I thought, well maybe it is just something that will disappear and, you know, they don't seem too worried about it so I left it for a long time and I went back again on 10th May.' [23, F, 21-30]*

Table 4: Workshop participants' views on how to improve GP consultations to reduce missed diagnostic opportunities

1	Ten-minute appointments or 'one symptom per appointment' are not sufficient to share subtle, intermittent changes/symptoms and can lead to selective or limited disclosure.
2	Vague symptoms need thorough exploration by family doctors. Take a good history from family and friends if not forthcoming from the patient as patients may not notice all the symptoms themselves.
3	Improve how patients present their symptoms in the consultation (e.g. encourage patients to bring written lists of symptoms, track multiple symptoms and voice any concerns)
4	Aim at continuity of care so that GPs can have increased awareness of symptom changes over time.
5	Encourage follow-up appointments by making them before a patient leaves the surgery or giving a time limit for symptoms to resolve.
6	Empower patients to return if they think something is wrong or if they are unhappy with the plan.
7	Identify patients with repeated consultations with vague symptoms and have lower threshold for referral based on GP intuition.
8	When ordering investigations, most patients would rather be told that cancer is a differential diagnosis
9	Can GPs have easier access to MRI scans and reduced waiting times?

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